

Navigating Life's Final Journey

*Conversations,
Choices,
Resources*

Choosing Your Own Path

By Pat O'Connor

Endorsements for Navigating Life's Final Journey

A must read for healthcare professionals and those wanting to take control of end-of-life decisions for themselves and their families.

As a retired nurse leader, I have found this to be an often overlooked topic that has made the healthcare system challenging and painful to navigate for many patients and families during the final stage of life. This book is easy to read and understand: a wonderful resource with heartfelt illustrative stories.

**Cynthia A. Coughlin, MS, BSN, Retired Senior Vice President of Patient Care/
Recipient of President's Award NH Hospital Association**

Pat O'Connor has written a "must read" book full of compassion, understanding, and helpful suggestions as we face the reality of end of life with dignity and peace. She shares her experience as a board-certified nurse practitioner with a specialty in hospice/palliative care offering short stories of patients and practical ways in which they were helped. This book should be in every doctor's office, senior living complex, and nursing home, as a help for both patients and family members in understanding the importance of asking questions and listening for the answers as decisions are made for end-of-life care. She offers a pathway of stones to follow, one step at a time, through the ups and downs of this difficult journey. Resources, including a glossary, are included. I speak with personal experience of Pat's care, and all that she offers in this book as she helped me through my husband's final journey.

**Marjorie Burke, author of the Melting Ice ~Shifting Sand
trilogy on Alzheimer's disease**

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Dedication

I dedicate this book to the memory of David Ross Russell, MD – my colleague, my mentor, my friend. David’s brilliance, dedication, and compassion have inspired and informed my practice since we met over thirty years ago. I hope that with this book I can further serve patients and their loved ones in a manner that would make David proud!

NAVIGATING LIFE’S FINAL JOURNEY
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I would like to credit Rich and Cindi Coughlin and my husband, Tom Ange, for helping me to create the cover cairn! Photography by the author with editing of photograph by Tom!

Chapter Page artwork by Tom Ange.

All of the patient stories are told to the best of the author’s recollection. The names and some small details have been changed to protect the privacy of the individuals concerned.

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Preface: The Current State of Affairs

We are predominantly a death-denying society. The medical culture of the United States is geared primarily toward curing acute illness, controlling chronic disease, repairing trauma, and preventing heart attacks, strokes, and other maladies. Our system works for a cure or, when that is not an option, to delay disease progression and increase life span.

There often comes a time, though, when medical lengthening of life is not what a person wants. People who are seriously ill often are aware before their medical providers that their life expectancy is limited. They may not want to burden anyone with a conversation about their private thoughts. When chronic illnesses enter the final stage or terminal illness happens, people may be ready to let the end come naturally. Families live with grief and ambiguous loss as they witness the prolonged suffering of their loved ones. Spouses suffer financial collapse trying to find services to care for partners who can no longer care for themselves. Caregivers suffer physical, emotional, and spiritual collapse as they try to “do it all.” Delaying natural death can also result in the development of further illnesses, including dementia.

When people have no one who can care for them at home, or those who have been giving that care are burned out, people might have to go into a nursing home. Despite the best efforts of the staff at these facilities, they can be just “waiting rooms,” places to merely exist until death. The quality of care in these facilities varies, it is quite expensive, and it just is not home. It’s easy to see why people often say they would rather die than live beyond their ability to care for themselves at home.

Another frequent stop when people are nearing the end of their lives is the intensive care unit. The ICU can be a fabulous gift to people whose medical conditions are reversible. However, when someone ends up in the ICU because their body can no longer sustain life on its own as the result of an irreversible cause, the ICU is not so much of a gift.

Spend any time in an intensive care unit and you will likely question our current medical model.

Unfortunately, many in the medical community are reluctant to tell people they or their loved ones are dying. So either dying people end up receiving invasive care with medications and machines until their bodies finally die despite all efforts to keep them alive or their loved ones are forced to face the decision to “pull the plug.” This decision is monumental for people who do not understand they are not causing death but simply allowing the dying process, which has been interrupted, to continue naturally. The cost of this culture of medicine is huge, both financially and in terms of human suffering.

People often speak of a “sudden death” as being merciful. They express gratitude for suffering spared when the course of a terminal illness is not prolonged. Yet they are unaware that there are choices they can make in advance, which they have the right to make, that determine whether their life is prolonged when their condition is irreversible. They have a right not to have their “exit ramps” blocked.

Dave and Annie's Story

I was once asked to facilitate a conversation with Annie and her husband, Dave. Dave was suffering moderate dementia and was on a downward trajectory. He had written advance directives years earlier, and Annie wanted to try to ascertain if he felt the same now as he had when he completed the papers. Previously, he had stated he did not want artificial prolongation of his life. He was able to confirm this decision when we talked.

What struck me in this conversation was something Annie lovingly expressed. She was devoted to Dave. She had quit her job and was doing everything possible to keep her husband at home. She looked at me and quietly, tearfully said, “I just hope his heart disease takes him. I don't want him to suffer. I want him to die before his dementia gets real bad.”

Unfortunately, this desire was not what had guided recent decisions about Dave's medical care. A couple of months before, Dave had stents

put into his heart for his coronary artery disease. His cardiologist did what cardiologists do; he restored circulation in the heart to keep Dave from having a fatal heart attack. Annie did not recall any discussion with the doctor regarding Dave's previously stated directives for care. There was no conversation with her, as Dave's activated (now officially recognized as making decisions) Health Care Agent, about what she believed to be his goals of care.

If their medical professionals do not ask the questions, people are reluctant to speak of goals that may not be in line with prolonging life in any way necessary. It is difficult to speak the wish Annie did, for Dave to die before things got worse. Yet, she said it out of the utmost love. Somehow, these feelings and choices must be heard and respected. People must be empowered to speak their truths. Medical providers must ask the questions and hear the answers. Only then do people have a chance of being given the care they choose for the end of their lives.

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Many have heard the plaintive cries of the frail elderly who wish their lives were over. They speak of “praying each night that the good Lord will take me by morning.” They talk about being ready, so ready, to die; they describe feeling as if they have lived their lives and now are burdens on their families. They express the desire for ceaseless pain and suffering to be over. Some seek physician aid in dying as a way out. This picture is a truth being lived by many people and their families. It is also a scenario that might have been avoided if we had honest, direct conversations with our families and our medical caregivers.

It is not the responsibility or the right of the medical community to decide the goal of care for each individual. You deserve to make your own, informed choices. Transparency in health care is imperative; honest, hard truths must be told; and people must be given choices while they can still make their own decisions.

Conversations must be had!

Chapter One

The True Beginning: My First Consultation

Matthew and His Dad's Story

